

Autism Unveiled

In a personal journey, an anthropologist charts how society — and his own family — deals with this increasingly common disorder

By RICHARD MONASTERSKY

Roy Richard Grinker started his training in psychiatry before he hit puberty. As an 11-year-old growing up in Chicago, he spent Saturday afternoons getting his medical education at the home of his grandfather, a seminal figure in American psychiatry. In one-on-one seminars, the young boy learned how to diagnose manic depression and schizophrenia and how not to confuse the two — as some doctors were prone to do in the early 1970s.

In sixth grade, Mr. Grinker wrote a review of *The Interpretation of Dreams*, something of a bible in his family because his grandfather had undergone analysis with Freud. Mr. Grinker's father and great-grandfather were also successful psychoanalysts, and he was groomed to enter the family business.

"I worked really hard as a kid to try to love psychiatry as much as my family did, but they were so good at it that I was scared of not living up to them," says Mr. Grinker, who decided to flee intellectually from his forebears during college. He refused to take science courses, and thereby closed off the path to medical school. He pursued a Ph.D. in anthropology, did fieldwork in Africa and South Korea, and eventually settled into his current job as a professor of anthropology at George Washington University.

But the academic wanderings over the years have brought him right back home in his most recent project, which marries anthropology with psychiatry in an attempt to make sense of an intensely personal issue: his own daughter's autism.

In his new book *Unstrange Minds: Remapping the World of Autism* (Basic Books), Mr. Grinker analyzes how psychiatric

understanding of autism has changed over the decades and how those shifts have influenced society. In recent years, the numbers of people diagnosed with autism and related disorders have shot upwards. Government statistics released this year suggest the condition now affects one in 150 American children. The surge has raised fears that an epidemic is sweeping through the nation, with some parents blaming vaccines for their children's autism.

That claim, rejected by most doctors, will be the focus of a federal court hearing scheduled to begin next month. And Mr. Grinker marches straight into this controversial arena by arguing that the epidemic is actually an illusion.

The rates have gone up, he says, because doctors have broadened the diagnosis to include more people — and because society is more willing to see autism and other mental disorders. Children who were once hidden behind the doors of institutions or a family's back bedroom are now marching with their parents to demand more research. Those same children are also entering public schools, and even growing up into adults who blog about bigotry and the need to accept what they term "neurodiversity."

As he talks in his book about the rise of autism, Mr. Grinker opens the door to his own family and their attempts to help and understand his daughter Isabel, who is now 15. "I felt like when I was writing this book that my daughter's life was a microcosm of what we're seeing elsewhere — the growth of understanding," he says.

It is an uplifting story, but not without some painful episodes that Mr. Grinker shares in his unvarnished tale of life with an autistic daughter. When Isabel was just a toddler, a prominent psychiatrist blamed Mr. Grinker's wife for their daughter's disorder. Later a principal physically abused the young girl at school because she couldn't sit silently at lunch, he says.

Then there are the times when Mr. Grinker's own stamina runs dry, after an evening of providing the limited foods she tolerates, avoiding the noises that set her off, coaxing her to answer simple questions, and generally contorting his thoughts in an attempt to

comprehend hers. In one scene, he admits that life with his daughter can sometimes take so much effort that he feels more affection for her at night, while she sleeps.

Married to Psychiatry

In his office at George Washington, lined floor to ceiling with books, Mr. Grinker, 45, does not shy away from psychoanalyzing his own career. There was the Oedipal struggle of whether he could supplant his father and grandfather as a psychiatrist. Then came his first book, in which he set out to debunk the work of the famous anthropologist Colin M. Turnbull. Mr. Turnbull once held the same faculty position at George Washington, and both of them studied the Pygmies in present-day Congo.

In the end, Mr. Grinker says with a smile, the father figures won. After learning to appreciate Mr. Turnbull's work, Mr. Grinker wrote a biography called *In the Arms of Africa: The Life of Colin M. Turnbull* (St. Martin's Press, 2000). "I ended up," he says, "regretting the immaturity of my youthful desire to slay the father."

Though Mr. Grinker thought he defied his family by pursuing anthropology, in truth he never ventured far from their chosen field. In graduate school, he fell in love with a young Korean-American doctor, Joyce Y. Chung, who had recently completed her training in psychiatry. When Mr. Grinker wrote the Turnbull biography, he was in essence conducting an analysis of the scholar. And then circumstances forced Mr. Grinker to learn more about mental disorders as he tried to raise his oldest daughter.

But he went further than most parents of autistic children. Because Mr. Grinker is an anthropologist, friends and acquaintances often asked him about autism in other cultures, and he could not answer their questions. So he began to do research, both about other countries and about the changes in American culture. "I started to delve into psychiatry and psychology, and one day, when I was deep into it," he says, "my wife looked at me and said: You know, you're doing psychiatry now."

Some of the conclusions he reached drew on the lessons learned

more than 30 years earlier, in those Saturday-afternoon sessions with his grandfather, who was at the time struggling to modernize his own field. Roy R. Grinker Sr., had started the department of psychiatry at the University of Chicago and had served as founding editor of the *Archives of General Psychiatry*. Although influenced by Freud, Dr. Grinker had tried to publicize the limitations of traditional psychoanalysis and was pushing to make psychiatry more scientific. At the time, there were no well-accepted diagnostic standards, so doctors did not agree on how to distinguish one mental disorder from another, says Mr. Grinker.

In publications and in classes, his grandfather urged psychiatrists to use more standard, quantitative methods — a plea that prefigured the publication in 1980 of the third edition of the *Diagnostic and Statistical Manual of Mental Disorders*, known as the DSM III. That volume, the first to incorporate a growing body of empirical work, provided physicians around the world with a uniform set of criteria upon which to base their diagnoses.

But the DSM is a moving target because with each subsequent edition, the standards have changed. For autism, the more recent DSM volumes include people who were not captured by previous versions. For Mr. Grinker, that helps explain a major part of the rising autism numbers.

An Unseen Disorder

When Mr. Grinker's daughter was diagnosed, in 1994, she was two and a half and used only a handful of words, which did not include "mommy" or "daddy," "yes" or "no." She used no verbs, only a selection of nouns consisting mostly of Disney characters and the names of trains from "Thomas the Tank Engine."

At the time, American society was just as inarticulate about Isabel's condition. Few people knew much about the disorder, and even medical specialists were relatively ignorant. Mr. Grinker's wife had done her psychiatric residency at Massachusetts General Hospital, one of the best in the nation, and had never seen a case of autism.

The year of Isabel's diagnosis, Mr. Grinker writes in his book, "our local public-school system regarded her as if she were from outer space. Autism was a strange word to most people." When the family went out, few people understood why his daughter interacted with others so oddly. In many ways at that time, Mr. Grinker knew just as little about autism as most Americans.

As he learned more about the disorder, so did the rest of the country. High-profile parents and relatives of autistic children started to publicize the syndrome. Doug Flutie and Dan Marino, both NFL quarterbacks with affected sons, set up foundations to help children with autism. Don Imus took up the cause on his radio show.

Temple Grandin, a professor of animal science at Colorado State University who was diagnosed with autism in the early 1950s, says the situation has improved markedly in some respects. "We have a lot more services for the more severe cases," she says. Also, some schools have learned to accommodate the needs of students with autism by not forcing them to endure situations that overload their senses, such as noisy lunchrooms and gyms.

But Ms. Grandin has concerns about the way the education system treats children with Asperger's syndrome, a milder form of autism often marked by high intelligence coupled with social deficits. In the past, such children would have gone through school with the label of "geeks and nerds," she says, whereas today they receive a special-education plan. "One thing I worry about with Asperger's is getting into the handicapped mentality," she says. "I'm seeing Asperger's kids with IQs of 150 going down the special-ed run, and they shouldn't be."

In recent years, advances in technology have made a huge difference for people with autism, says Morton Ann Gernsbacher, a professor of psychology at the University of Wisconsin at Madison and president of the Association for Psychological Science. Her 11-year-old son, who is autistic, was able to work around his speech problems by learning how to communicate via a modified form of typing.

In her own work, Ms. Gernsbacher collaborates with an autistic researcher through e-mail, which removes many of the problems that people with autism face in oral communication.

"Asynchronous communication is ideal for autistic individuals," says Ms. Gernsbacher. "It takes away face-to-face demands. It takes away timing demands."

Like Mr. Grinker, she has noticed a transformation in the way America treats people with autism. "The news media has brought autism wonderfully to the public's attention," she says. That helps explain the increasing number of autism diagnoses, she says. "My opinion is, this is a good thing. Individuals who need services deserve to get those services."

Autism Around the World

In some other countries, the situation remains far different. For his book, Mr. Grinker conducted fieldwork in India, South Africa, and South Korea to document how those cultures treat people with autism. In India relatively few people are diagnosed with the disorder, he says. Most of the people who would fit that classification in the United States are considered in India to be mentally retarded or mad. When Mr. Grinker visited a prominent pediatrician in Delhi, the doctor said, "I wouldn't know if an abnormal child in my office had autism or not. I would just know he was abnormal."

In South Korea, Mr. Grinker found, doctors often give autistic children the diagnosis of reactive attachment disorder, which is thought to occur when mothers fail to bond with their children. Although that diagnosis blames the mother for the child's problem, some families prefer it over autism because it does not imply a permanent condition. What's more, a disorder with genetic links, such as autism, stigmatizes the entire family, making it harder for the affected person's siblings to marry. The value of a family's apartment can drop if a child receives an autism diagnosis, says Mr. Grinker.

But even in the foreign cultures that he studied, the situation is starting to open up for people with autism. In 2005 a movie called

Marathon became a hit in South Korea and gave many people in that country their first glimpse of the disorder. Based on a true story, the movie portrays the struggle of a young autistic man, who earns respect and independence through long-distance running.

Just a decade earlier, residents in Seoul had violently protested the establishment of a school for autistic children in their neighborhood, says Mr. Grinker. They assaulted school personnel and cut its phone lines. "They said they didn't want their children to see or meet a child with autism," Mr. Grinker writes. By 2005, however, the neighborhood came to not only accept the school but to embrace it. Local residents now volunteer there and use the school gym for concerts.

Some of the energy driving such changes originates half a world away, in the United States. Parents in other countries often gain knowledge and hope from Web sites set up by advocates and organizations in the West, he says.

"I'd really like parents to know," he says, "that when they go out on a walk or a jog to raise money, or they go to a fund raiser, or they talk or write about autism awareness, that the payoff isn't just in this country, or in their local community. For all they know, the payoff is for a woman in the hills of northern India, who doesn't know how to understand her son and what's happening with him."

Risks of Exposure

That is part of what motivated Mr. Grinker to tell his daughter's tale, even though it meant exposing her and the rest of his family. He and his wife worried about how Isabel would feel and whether the publicity would cause her harm. His wife, he says, "has been better about helping me set limits: How much of our lives do we disclose? How much of our daughter do we disclose? Do we allow her to be on TV? Do we allow pictures of her?"

When a national television show, *The View*, requested to interview Mr. Grinker, he turned down the opportunity, he says, because the show's staff wanted his daughter to appear as well. He has declined any requests to interview or photograph Isabel, although some

publications have been permitted to use childhood photos of her.

Ms. Gernsbacher, of Wisconsin, has been similarly wary about exposing her son, even though the precocious 11-year-old now posts his own videos on YouTube, writes for his high-school newspaper, and lobbies for the rights of autistic people. A few years ago, when Ms. Gernsbacher wanted to describe in a scholarly publication the remarkable progress he has made despite his speech problems, she veiled his identity by writing a case history of an unnamed boy. There were enough clues in the article, however, that "many people have figured it out," she says.

Mr. Grinker's daughter has also developed far more than many people would have imagined possible. Now in high school, she is learning algebra and has become an accomplished cellist. She excels in French class, has a commanding knowledge of animals, and wants to be zookeeper. But the landscape of human social interactions is still an alien terrain, full of unwritten and complex rules.

When it came time for Mr. Grinker to title his book, he chose the word *unstrange* because it captures the essence of what anthropologists do. They make the foreign less strange. It's also a task that his family has personally had to work at every day, to see life through Isabel's eyes, even as she struggles to navigate through a world not designed with her in mind.

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The Autism Unveiled Project is a six-week project where people on the autism spectrum share their uniqueness. The kick-off was Feb. 18 with blogs by Dr. Stephen Shore, Jennifer Oâ€™Toole and Tito Rajarshi Mukhopayday. Each day through April 2, 2015, the Art of Autism will post 2 blogs from people on the spectrum sharing who they are. The people who have chosen to participate share their gifts, their struggles, and their uniqueness. Theyâ€™ve also been asked to identify the word or words they use to describe their autism for the title.